

ARTICLE

PARENTING AND DISABILITY: THE FINAL FRONTIER

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My life was transformed on July 26, 1990. I sat in front of a television and became teary eyed as I watched President Bush sign the Americans with Disabilities Act (ADA).¹ He declared that the ADA was the beginning of “a bright new era of equality, independence, and freedom” for the then estimated 43 million people in the United States living with a disability.² I was overjoyed. I believed that the ADA would end discrimination against people with disabilities. After forty years of progressive legislation designed to empower people with disabilities, disability rights law had reached its zenith. Millions of people with disabilities were not going to be barred from employment opportunities. The ADA would ensure that accessing mass transportation would be easy and accessible housing was going to become commonplace. There was no question the ADA was going to revolutionize my life and the lives of countless others. I was an American and now shared the same civil rights as those Americans without a disability took for granted. I was a true believer.

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1. *George H.W. Bush at the Signing of the Americans with Disabilities Act on the South Law, 1990*, C-SPAN, <http://whitehouse.c-span.org/Video/ByPresident/George-H-W-Bush-Signs-ADA.aspx> (last visited Jan. 26, 2015). With the 25th anniversary of the ADA nearing, many have written about how the ADA was passed into law. The best text that reveals the trials and tribulations of those who played key roles is FRED PELKA, WHAT HAVE YOU DONE: AN ORAL HISTORY OF THE DISABILITY RIGHTS MOVEMENT (2012).

2. *Remarks of President George Bush at the Signing of the Americans with Disabilities Act*, EEOC, http://www.eeoc.gov/eeoc/history/35th/videos/ada_signing_text.html (last visited Jan. 26, 2015).

In the years that followed, I held a barbeque every July 26th and called that day my Independence Day.³ Not one of my friends understood the importance of the ADA. Unlike the great Civil Rights Act of 1964, the ADA was passed with virtually no public debate.⁴ This was not accidental. A small cadre of disability rights lobbyists and activists believed entrenched stereotypes about people with disabilities would mislead legislators. Disability rights was a hard sell. If a rigorous national debate took place over the meaning of disability discrimination, they feared the ADA would not be passed into law.

The strategy of avoiding a broad-based discussion of the ADA was a double-edged sword. Once passed into law, the ADA would become the only major civil rights legislation that was poorly understood. Joseph Shapiro argued that the ADA was a stealth civil rights movement that bypassed the press and defied conventional wisdom.⁵

In retrospect, the decision to avoid scrutiny was not only wise but reflects the fact the ADA's birthright is not associated with any single individual. We, meaning people with disabilities as a disenfranchised minority group, have no famous figurehead such as Martin Luther King. The disability rights movement is made up of ordinary people whose existence challenged conventional wisdom. We were openly defiant and confrontational. We fought for the right to be educated in public school and universities.⁶ We advocated for accessible mass transportation and housing.⁷ I was but one among the many who "worked for years organizing and attending protests, licking envelopes, sending out alerts, drafting legislation, speaking, testifying, negotiating, lobbying, filing lawsuits, being

3. Although, I was not the only person using this phrase. *George H.W. Bush at the Signing of the Americans with Disabilities Act on the South Law, 1990, supra* note 1.

4. See NAT'L COUNCIL ON DISABILITY, EQUALITY OF OPPORTUNITY: THE MAKING OF THE AMERICANS WITH DISABILITIES ACT xiii, xvii (2010) ("Passage of the ADA is a story of political leaders on both sides of the aisle who put aside personal and partisan differences to do what they thought was right thing to do, . . . and kept the ADA from falling victim to a venomous public debate.").

5. Joseph Shapiro, *Disability Policy and the Media: A Stealth Civil Rights Movement Bypasses the Press and Defies Conventional Wisdom*, 22 POL'Y STUD. J. 123 (1994).

6. See generally Christopher P. Borreca & David B. Hodgins, *Education in Public School Students with Disabilities*, HOUS. LAW., Mar./Apr. 2014, at 12 (providing a basic overview of special education law).

7. See STEVE BROWN, FREEDOM OF MOVEMENT: INDEPENDENT LIVING HISTORY AND PHILOSOPHY 69 (2000), available at http://www.ilru.org/sites/default/files/freedom_of_movement.pdf (noting the iconic Denver sit-in demonstration by disability rights activists protesting Denver's completely inaccessible mass transit system); David P. Lazarus & Susan DiMaria, *Housing Discrimination and the Disabled*, N.J. LAW., July 1995, at 20.

arrested—doing whatever they could for a cause they believed in[.]”⁸

I am proud of the part I have played in the disability rights movement and my academic contributions to disability studies and bioethics. Yet, here I sit nearly twenty-five years after the ADA was passed and know to the marrow of my bones that I will never be equal to those who have a typical nondisabled body. The social divide between a person with and without a disability remains as vast as it was in 1990. Of course, the ADA has helped many people with disabilities, but, when these gains are measured against the daily reality experienced by those with disabilities, the law merely calls attention to the gross lack of equality. In essence, I remain cut off from routine social interaction. Alienated from society, I work very hard not to withdraw. I despise the looks of pity my presence sometimes prompts and more than once a stranger has told me, “I would rather be dead than be in a wheelchair.” I rail against the low expectations and praise I receive for doing something as routine as get in and out of my car without assistance. Like my mentor, Robert F. Murphy, who was a distinguished anthropologist and quadriplegic when I met him at Columbia University in the 1980s,⁹ I believed disability was defined by society and given meaning by culture; hence, disability was a social malady. In short, I have a social disease.

I am the antithesis of disability-based stereotyping. Since the day I was paralyzed in 1978, I utterly and forcefully rejected the stigma associated with being disabled. With the strong support of my family, I rejected the suggestion that my life was less valuable than typical bipedal people. I have, as a result, led an ordinary life: I went to college and graduate school; earned my Ph.D. in anthropology with distinction; got married; had a son, Thomas; and, even, got divorced. I have struggled with employment my entire academic career. None of this is out of the norm for a person without a disability.¹⁰ For a person such as myself to do the ordinary is out of the norm. One of those norms that I was not expected to accomplish was becoming a father. As a paralyzed man, I was not considered to be “parental material.” How do I know this? My ability to be a parent has been openly questioned

8. Arlene Mayerson, *The History of the Americans with Disabilities Act: A Movement Perspective*, DISABILITY RIGHTS EDUC. & DEF. FUND, <http://dredf.org/news/publications/the-history-of-the-ada/> (last visited Jan. 26, 2015).

9. Alfonso A. Narvaez, *Robert F. Murphy, 66, Professor of Anthropology and an Author*, N. Y. TIMES (Oct. 11, 1990), <http://www.nytimes.com/1990/10/11/obituaries/robert-f-murphy-66-professor-of-anthropology-and-an-author.html>.

10. See, e.g., UNITED NATIONS DEPT OF PUB. INFO., FACT SHEET: EMPLOYMENT OF PERSONS WITH DISABILITIES 1 (2004), available at <http://www.un.org/disabilities/documents/toolaction/employmentfs.pdf>.

by virtually everyone with which I have interacted: lawyers, doctors, nurses, teachers, plumbers, electricians, Boy Scout leaders, school administrators, and strangers all questioned my ability to be a father. Everyone had a negative opinion that they were all too willing to share with me.

By the vagaries of time and happenstance my son and the ADA bisect two distinct eras in disability history—life before and after the ADA. The discrimination people with a disability encountered prior to the passage of the ADA was blatant, and its intent destructive.¹¹ For example, I was an Eastern Paralyzed Veterans Association (EPVA)¹² bus buddy in New York City. I had to fight to get on a Metropolitan Transportation Authority (MTA) bus (at the time Mayor Koch was a staunch opponent).¹³ More than once I was spit on by one of my fellow New Yorkers, who eagerly told me that the money spent on a wheelchair lift was a waste of their taxpayer dollars. In the post-ADA era, discrimination is far more insidious and polite, though no less destructive. After my son was born, I was asked the same question every time I went out the door, “Are you the biological father?” As my son became older, this question morphed into, “So, how long after your son was born did you become you paralyzed?” The assumption was clear: paralyzed men do not father children. This false belief conveniently ignores the fact there are roughly 8 million families that include at least one person with a disability.¹⁴ The National Council on Disability released a comprehensive report—titled “Rocking the Cradle”—on parenting with a disability.¹⁵ Among the twenty findings, I found one indicative of how the ADA has failed to resonate culturally:

11. 42 U.S.C. § 12101(a) (2012); *see also* William Peace, *Being a Parent with a Disability*, BAD CRIPPLE (May 13, 2010), <http://badcripple.blogspot.com/2010/05/being-parent-with-disability.html>.

12. In the early 1980s, there was an ingrained belief that paratransit was the cheapest and most humane way to transport people with disabilities. This effort turned out to be a tinderbox, and the battle to get wheelchair lifts on public buses was heated and controversial. People with disabilities vigorously protested and were keenly aware of the fact that transportation was symbolically and practically of critical importance. Protests made national news, and by 1990, half of all public bus systems were replacing old buses with new, wheelchair lift equipped buses. For more on the victory to include wheelchair lifts on buses, *see generally* TO RIDE THE PUBLIC BUSES: THE FIGHT THAT BUILT A MOVEMENT (Mary Johnson & Barrett Shaw eds., 2001).

13. Edward A. Gargan, *After One Final Battle, Legislature Goes Home*, N. T. TIMES (July 2, 1984), <http://www.nytimes.com/1984/07/02/nyregion/after-one-final-battle-legislature-goes-home.html>; *see also* William Peace, *AC Transit and a NYC History Lesson*, BAD CRIPPLE (Jan. 20, 2014), <http://badcripple.blogspot.com/2014/01/ac-transit-and-nyc-history-lesson.html>.

14. *Let Your Parenting Journey Begin . . .*, PARENTS WITH DISABILITIES, <http://www.disabledparents.net/> (last visited Jan. 26, 2015).

15. NAT'L COUNCIL ON DISABILITY, ROCKING THE CRADLE: ENSURING THE RIGHTS OF PARENTS WITH DISABILITIES AND THEIR CHILDREN (2012), *available at* http://www.ncdsv.org/images/NCD_RockingTheCradle_9-27-2012.pdf.

there are simply few accurate or comprehensive sources of information on the prevalence of parents with disabilities.¹⁶

Rejecting the stigma associated with my disability is never easy, but it was made far more problematic when I became a parent. What I recall the most when I think back on my son's childhood and the ADA is that I became public property. Anonymity was impossible. Within weeks of my son's birth in 1992, it was clear to me I was the bogeyman. People feared for my son's welfare. Others, especially health care providers, questioned whether someone "in my condition" could safely raise a child. People without disabilities were not only setting the terms of the debate but also judging me harshly. The parental bar was set high for me because others felt free to ask rude and intrusive questions they would never ask a man that was bipedal. How do you change a diaper? How can you pick up your son if he falls? How can you bathe him? All of the questions assumed I was incompetent or physically incapable. No one thought about what I could do. In fact, not a single person that questioned my ability to be a parent thought they were being bigoted. Yet, that is exactly what they were being.

The worst bias I encountered as a parent with a disability was accessing immediate health care—specifically, emergency care. My son and I love the outdoors, and he was a rough and tumble kid. We enjoyed camping on a regular basis. My son liked to cook and whittle wood. Whittlers like sharp knives and, on more than a few occasions, my son got a laceration that required stitches. I vividly recall one camping trip my son got a severe cut with a very sharp pocketknife. I was not worried. I always packed an extensive first aid kit, and I carefully wrapped his hand in a gauze bandage and clean white hand towel. As we drove to the emergency room, he held his hand above his heart, but by the time we got to the hospital, the homemade bandage was bloody. Paper work was filled out, and the triage nurse came over to us and asked, "Who is the patient?" I looked at my son, and he looked at me in confusion. I was then asked, "What is the nature of my relationship with the child." I stated, "I am his father." She then asked if I had any legal documents or evidence that could prove this. Both my and my son's faces flushed in anger. I would think a bloody bandage made it clear who required medical attention. We then proceeded to a treatment room, and, when the physician appeared, the same set of questions was asked. On our drive home both of us were silent, and I thought of Mary Johnson, the longtime editor of *The Disability Rag*, a hard-hitting disability rights publication.¹⁷ In an

16. *Id.* at 16.

17. *WIMN's Voices: A Group Blog on Women, Media, AND . . . Mary Johnson*, WIMN, <http://www.wimnonline.org/WIMNsVoicesBlog?author=26&profile> (last visited Jan. 26, 2015).

interview about the film *Million Dollar Baby* in *Counter Punch* she stated:

The truth is that the real problems a disabled person faces are caused by a society that refuses to see the condition of disabled people as being a result of bigotry, discrimination, and flawed social policies emanating from the belief that nothing can really be done for a disabled person if they can't be cured or made "better" physically.¹⁸

As a parent with a disability, I learned in a visceral way that the ADA cannot change the social perception of disability. What I learned raising my son, and living with paralysis since I was eighteen years old, is that disability rights are quintessentially human rights for all people. What the ADA has accomplished is to put the letter of the law on our side. By itself, this is progress. A system of legal protections exists, but what use is the law when there is no social mandate or support for it. Worse, there are many who bitterly complain about the costs associated with ADA compliance.¹⁹ Some insist the ADA is an unfunded federal mandate and an odious burden.²⁰ The ADA's impact has been limited socially.

We, as a society, have the power to change the existing social and economic variables that needlessly limit the lives of people with disabilities but elect not to change those variables. This failure is evident every time I travel. In spring 2004, my son and I visited the Udvar-Hazy Center outside of Dulles National Airport.²¹ We are aviation buffs and were thrilled that the Smithsonian Air and Space Museum had created a huge museum—40 million cubic feet—to display its breathtaking collection.²² What should have been a wonderful father-son

18. Mickey Z., *The Million Dollar Interview: Talking to Mary Johnson About Clint Eastwood, Hunter Thompson and the "Right to Die"*, COUNTERPUNCH (Feb. 28, 2005), <http://www.counterpunch.org/2005/02/28/talking-to-mary-johnson-about-clint-eastwood-hunter-thompson-and-the-quot-right-to-die-quot/>.

19. See Casey L. Raymond, Note, *A Growing Threat to the ADA: An Empirical Study of Mass Filings, Popular Backlash, and Potential Solutions Under Titles II and III*, 18 TEX. J.C.L. & C.R. 235, 238–40 (2013).

20. The Cato Institute, for example, took this position, arguing that the ADA was "one of the more costly unfunded mandates[.]" CATO INST., HANDBOOK FOR CONGRESS 65–69, available at <http://object.cato.org/sites/cato.org/files/serials/files/cato-handbook-policymakers/1995/9/104-7.pdf> (last visited Jan. 26, 2015).

21. *Udvar-Hazy Center in Chantilly, VA*, SMITHSONIAN NAT'L AIR & SPACE MUSEUM, <http://airandspace.si.edu/visit/udvar-hazy-center/> (last visited Jan. 26, 2015).

22. *Nat'l Air and Space Museum Soars: \$311 Million Museum Opens Monday, Dec. 15*, CONNECTION, <http://www.connectionnewspapers.com/news/2003/dec/11/natl-air-and-space-museum-soars/> (last visited Jan. 26, 2015); William J. Peace, *The Smithsonian Shuttle Incident*, RAGGED EDGE ONLINE, <http://www.raggededgemagazine.com/life/smithsonianbus.html> (last visited Jan. 15, 2015).

experience turned into something quite different.²³ With concerted effort, I was able to discover a Smithsonian shuttle bus with a wheelchair lift that would take visitors from outside the Air and Space Museum to the Udvar-Hazy Center. I had promised my son he could use a flight simulator at the new museum. Lines were hours long, and if we did not get on the first bus, my son would not be able to try the simulator. After every single person got on the bus, the driver tried to figure out how to use the lift. Much time was spent trying to get the lift to work, but it was clear that the driver had to leave. I could assert my civil rights and not crawl up and onto the bus. This would have, undoubtedly, ruined our trip. There was no solution to this dilemma, and, much to my regret, I crawled onto the bus. This is my lasting memory of the trip. The lesson my son learned and would remark on every time we encountered needless access barriers was “Dad, no one cares.” There was no Rosa Parks support for me or others with disabilities.

My son was and remains correct: no one cares. There is a hazy idea that a law called the ADA was passed a long time ago, which solved all the problems people with disabilities encounter. This is not only wrong but fantasy. The only conclusion I can draw from my experience raising my son is that there is a divide between what the ADA mandates and the reality I experience as a wheelchair user.

My son and I were lucky to travel extensively when he was a child. At no point in my life was I more aware of my stigmatized social status. Time after time we encountered problems with planes, buses, rental cars, trains, and hotels. All are required by law to provide accessible services,²⁴ but, virtually every time I traveled, I found lifts on buses broken, the ADA accessible room occupied or grossly inaccessible, the car with hand controls lost, and the special wheelchair lift filled with trash. All this happens despite repeated confirmations, in writing and over the phone, that access would be “seamless.” When I appeared with my son people look stunned, and a different reality existed.

I am not optimistic that I will ever be truly equal to others without a disability. I am pessimistic, in part, because I have become the cranky guy at various academic or public meetings. I am the narcissist in the back of the room complaining about the lack of access. I am the lone scholar advocating for himself. This perception individualizes my disability and is grossly misleading.

23. Peace, *supra* note 22.

24. Paul Stephen Dempsey, *The Civil Rights of the Handicapped in Transportation: The Americans with Disabilities Act and Related Legislation*, 19 *TRANSP. L.J.* 309, 321–28 (1991).

The lack of physical access and representation of scholars with a disability is indicative of a much larger social problem scholarly organizations do not want to address. Again and again, I hear we want to make the event I am attending accessible, but it is just too expensive. We would love to have you be a part of the event but see no way your special needs can be accommodated. Here is what is conveniently ignored: I am not advocating for myself. I can manage by myself quite well. I have spent the last thirty-eight years thinking out of the box and adapting to a hostile social and physical environment. I am advocating for the typically disenfranchised person with a disability: the man or woman who lacks a basic education and is living on the edge of poverty.²⁵ My son was right. No one cares. If people cared, if access and inclusion were valued, all events and buildings would place great importance on access for *all* people, including those with disabilities. That is not the reality I encounter. It was not the case when my son was born in 1992. It is, certainly, not the case today.

At Syracuse University, where I teach, my students are shocked by disability history. I have had more than one vividly upset student state, “This is a violation of human rights and it is unknown.” Worse, they quickly grasp that progress has been made. They make the intuitive leap that, had I been born in the pre-World War II era, I might not have been permitted in public. Ugly laws were common and the diseased, maimed, and mutilated were not allowed in public.²⁶ Institutions were created and another generation of people with disabilities were lost, their lives destroyed. The ADA has helped, but significant practical and social progress has proceeded at a glacial pace. I would suggest that people need to embrace the slogan widely used in the disability rights movement: “Nothing about us without us.”²⁷ We need qualified people with disabilities in positions of power. Only then can we stop well-meaning people who have no conception of disability rights and history from trying to provide a reasonable accommodation for those suffering from a disability. Young, qualified people with disabilities abound thanks to the ADA. The first generation of post-ADA adults is coming of age. They are filling classrooms, graduate and undergraduate institutions, and I

25. Rebecca Vallas & Shawn Fremstad, *Disability Is a Cause and Consequence of Poverty*, TALKPOVERTY.ORG (Sept. 19, 2014), <http://talkpoverty.org/2014/09/19/disability-cause-consequence-poverty/>.

26. See *Freedom Friday: A History Lesson on the Persecution of People with Disabilities*, FREEDOM RESOURCE CENTER FOR INDEP. LIVING, INC. (Nov. 15, 2013), <http://www.freedomrc.org/2013/11/15/freedom-friday-history-lesson-persecution-people-disabilities/>.

27. Disability activities used the phrase “nothing about us without us” beginning as early as the 1980s.

hope that they will become a force to be reckoned with—these are the people whom I dream of having a better future. A future free from the sort of discrimination I encountered.